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HMPRG 1115 Waiver draft application coment submission

Via email to HMPRG

Critique of Proposed Program Description

The largest issue with this proposal is its deafening silence on rural medical service delivery in five ways: resources, travel issues, digital infrastructure, first responder network, and location issues. The proposal also does not speak to the historic, cultural, and economic factors which bear upon southern and central Illinois directly affecting the outcome of medical service delivery under ACA. The proposal must be rewritten with greater sensitivity in these ways:

Add rural perspective. Throughout the proposal, the word "rural" is rarely mentioned while Chicago and its institutions, are mentioned by name 9 times with 5 paragraphs devoted to Chicago! There are 101 other counties in this state and not one was mentioned! A 465 bed hospital, run by U of I, it will not help a patient on Perry County. This is a page-by-page review on each topic

Page(P) 23: workforce education does not mention those institutions outside Chicago which already offer health care training like LLCC. 24:"HPSAs"; how many in rural, urban; contrasted with cosmopolitan areas? Silence P25: "underserved areas"; how many are rural, urban or cosmopolitan? Silence P26:"number of providers"; how are these arrayed in rural, urban, vs. cosmopolitan areas? Silence P27: "RHCs" no number, no affiliation, no location and *no plans for expansion* mentioned. At least it was not silent! P28: No mention of a "circuit-riding" or roving outpatient care program for rural areas. P29: "Training sites" have no mention of incorporating rotations in rural clinics or hospitals into training. It does not address the skilled persons who are aging with no replacement. There is one person who makes dentures in Springfield who has tried to retire twice. He is 81 and

back to work. P30: "..array…LTSS"; these are very limited in rural areas to begin with. Closing them would be a disaster. P 36:"..community opportunities for ID/DD persons"; how does that work for those living with their families on a farm? Silence P47: "performance evaluation for health disparities"; does not mention taking rural factors into account. Silence P48: "…100% of FPL" does not describe breakdown of populations in rural, urban & cosmopolitan areas by FPL. P52, Pargraph 1:"personal service not available"; this is a crying need in rural areas but rural is not mentioned in the proposal. Silence P52, Paragraph 2:"Service..limited by cost maximum except for transportation [to]..100 hours per month". Rural areas not only have larger distances, but poorer road systems, not plowed in winter. Therefore taking more of that 100 hours just to reach the patient. Factors are not mentioned in the cost maximum yet create a larger cost for service delivery. P 63-64: "Home access modifications"; rural areas have many older homes with round plugs, no ground wires, and cloth-covered wiring. Even plugging in a circulating mattress would require modifications. Many also need external access modifications. The expense limit proposed may not cover all the costs. P66: "family caregiver absences"; only allows for being away from the home. That does not account for the planting and harvest seasons when vulnerable persons are de-facto alone in the house in rural areas. Silence P70:"…individual counseling"; does not mention culturally congruent counselors and how this service would be accepted, much less delivered in rural areas. Silence *HMPRG must reconsider the whole medical resource delivery system for rural areas.*

<u>Distances and travel are major factor in medical service delivery in rural areas</u>. P46: "caseload and cost estimates": Effectively managing a caseload in rural areas means taking the travel factor into account. The proposal is silent. P53: "Adult day care transportation…" could be a real boon to rural families: rural conditions not mentioned nor the higher cost. P 58: "Facility-based day habilitation…" would encounter the same transport issues. P 68: "Transportation provided from patients' residence .. employment site.."; does not speak to those who live in the country. P 70: "..service provider must accept HFS payment..in full..[to] provide services in the home". What if the home is on a farm? The proposal does not mention travel or distance factors. These mean the counselor can only see one patient for every three seen in office. Thus, it is not economically viable for private counselors to accept less funding and bear greater costs. Such professionals are scarce in rural areas already. Not only must he counselor drive to patients, they must drive to the counselor. Medicare does not reimburse for doctor appointment transport. Trains, like the inter-urban from Quincy to Champaign no longer operate. Buses and taxis do not run very far outside town limits. *HMPRG must factor in both distance and travel conditions because these make the biggest difference in medical service delivery in rural areas. Homes on the range can not reach Patient Centered Medical Homes!*

The digital divide deepens farther down the State. P2: my comment: WIFI is not universal, many places have dial-up or DSL service only. At the southern-most counties, the topography interferes with transmission. A facility may have the software but not be able to transmit as quickly or as reliably. On my tour of all AAAs in 2006, I was sent something that did not "reach" me until two days later when I arrived at the East St. Louis area. Digital providers have virtual monopolies in their areas. As such, they have no incentive to upgrade equipment. Trying to send as much digital data as proposed relies on a system not able to carry digital freight as consistently and as universally as in Chicago. P10 15: digital connection with IDOC in Chicago does not refer to all the other prisons in the state. Given the digital difficulties, how does that system replicate everywhere? P 17:"rural access to specialists"; reliance on telemedicine to bridge gaps in care for rural areas must realize that the "tele" in southern Illinois is questionable. P 22: "..best available data used to inform health assessments"; assumes receiving all data, unscrambled, and in a timely manner. Don't count it. P 31: "UAT development" is silent as to rural issues as well as data distribution. If providers have the UAT but can't transmit the information it will not be useful to the system as a whole. How many rural entities are on the committee to draft the UAT? Do they come from Piat, Putnam, and Pope counties? *HMPRG has set s system on an assumed foundation which is not universal and therefore not reliable.*

The proposal does not speak to the issues of rural first responders. P 67: "Emergency Home Response Service" implies a level of coverage not found in rural areas. If the patient needs some one on-site; who? Some fire departments and ambulance companies are staffed by volunteers. The local radio had a story about a volunteer ambulance company that was about to shut its doors due to lack of funding. The required training is often located far, far away and only given during the growing season! Getting volunteers to give up their work at the busiest time of the year, travel away and at their own expense, is asking too much! Who will do this ER Home Response in rural areas? How does this proposal speak to the rural need for funding, upgrading, and localized training? It is silent. *HMRPG must do field discussions with rural first responders to address these issues before it can offer a reliable rural Emergency Home Response.*

Address location questions raised by the proposal: Where is it? The proposal did not come with maps or even references to PSA regions. P 3: "Two large regions"; does not describe the territory. Which PSA's? What city will be the hub in each? P 16"MTM pilot program"; where? P21: "isolated health systems"; where? P23:" provider supply not matched high demand in certain high-need areas.."; which ones are the HPSAs? P25: The proposal listed U of I & SIU but gave no location details. How many rural hospitals and clinics are affiliated and where are they? How many more will affiliate?

What are the territorial gaps in coverage? P 27: Rural Health Clinics were mentioned but not locations. Do they cover all areas?

Address local issues that could greatly interfere with the implementation of this proposal. The radio commentary about "Obama Care" is vitriolic down here. It's even worse from the far southern radio stations I can receive. **Successfully implementing this proposal requires speaking to the *residents' experience of medical service delivery* rather than marching under the banner of ACA.** It is for this reason that I plead with HMPRG to re-think and re-write this proposal. Nelson Mandela had a major cultural problem to unite the two South Africa(s); black and white. He put on the Springbuck's jersey when he attended their game! This proposal needs to "put on the jersey" to be successful. I lived for 30 years in Chicago and grew up in Central Illinois(back here since 2005). I can triangulate on these issues. Southern Illinois feels very slighted by Chicago. All the legislators will see the final proposal. If it does not speak to their needs, it will be actively disrupted but in subtle ways.

The each morning the farm price broadcasts make southern Illinoians aware we have a world-wide economic influence because of what we grow. In summer of 2012, our drought raised corn prices around the world. Yet, in our own state, southern Illinois is not even mentioned and the proposal speaks first about Chicago! There is even more wealth coming to southern Illinois in two forms. The first is "fracking". This process will create a boom-town affect with pressure on infrastructure, including on the medical service system. Illinois could have its own "North Dakota" problems. Making a more sensitive proposal now that speaks to rural needs could go a long way to gaining cooperation to manage care expansion later. Also at the southwest end of Illinois is our wine country. The vines are just getting established. Infrastructure is in very poor condition. When I was touring the AAAs, I had to "drive" across a stream because the pavement just stopped. Compared to California; Illinois about 5 years' behind. Illinois will catch up! Sensitivity and planning now will help us gain the cooperation of local residents and care for the additional demands as wine country develops.

There is a reason "Illinois ends in an "s"; there are at least three different cultures. For example, most people think Illinois was Union state in the Civil War. Actually, the very southern parts wanted to break off, form a new state, and join the Confederates! Unless this proposal "pushes the reset button", cooperation will break along these old cultural fault lines. All of Illinois deserves better medical care, especially in rural areas. We can make that possible.

Respectfully submitted, Sara L. Lieber, LSW